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Statement

**For Social Security Administration Compassionate Allowance Initiative
Hearing on Younger-Onset Alzheimer's Disease and Related Dementias**

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Good Afternoon, Commissioner Astrue, Social Security Administration officials and distinguished guests. For the record, I am Darby Morhardt, clinical social worker, director of education, and research associate professor at the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University Feinberg School of Medicine. I have been working with persons with Alzheimer's disease and related dementias and their caregiving families for the past 25 years. I appreciate the invitation and opportunity to speak to you today about the issues of persons affected by young onset Alzheimer's disease and related dementias. The many patients and families with Frontotemporal Dementia were pleased to see FTD placed on the Compassionate Allowances list in October 2008 and we are glad to see that you are considering the addition of Alzheimer's disease and related disorders to be added to this list. Families struggling with these neurodegenerative diseases at a young age have a host of psychological, social, family and financial issues that are different from those over 65. I have been asked today to discuss these in the particular light of those diagnosed with Primary Progressive Aphasia (PPA).

As you will hear from my colleagues, Drs. Mesulam and Weintraub, PPA is a diagnosis that typically presents in the 40s and 50s and one in which language problems are the only symptom for at least the first two years. It is considered a dementia because it is progressive and is caused by neurodegenerative disease that begins in language areas of the brain but progresses to affect many other areas over time. As a result, skills and abilities other than language gradually and irreversibly deteriorate.

As you will hear, these individuals may have intact memory and other social and behavioral skills, sometimes for several years after symptoms have started. This can cause much confusion to their families, friends, the healthcare professionals who are treating them, and patients themselves. There is increased risk of depression among persons with Primary Progressive Aphasia as they slowly lose the ability to speak, to understand others, to write, and to read at a time when they are still fully aware of their losses.

Planning for the family's financial security and for the education of children is daunting when an individual is faced with a dementing illness in the prime of his or her working

career. Affected persons in their 40s and 50s are often still working, saving for retirement, and have younger children whom they are supporting. Because of the patient's loss of employment, the well spouse may need to seek additional work to meet the family's financial needs. Simultaneously, the well spouse experiences the loss of intimacy and of a co-parenting partner. Young children suffer the loss of a parent at a developmentally tumultuous time of life. Young adult children who are normally separating from their family of origin and defining themselves and their own lives may need to be more involved in their family than their peers.

I would like to tell you about a gentleman I met recently in our clinic with a new diagnosis of PPA. This gentleman, whom I will call James, holds a PhD in clinical social work, has a private family therapy practice and is in the process of writing a book. He is 55 years old and lives with his wife and one teenage son who remains at home. Their other two children are in their twenties and in different cities. James has been continuing to try to work; however, recently told me that he cannot keep the names of his clients straight in his mind. He has increasing difficulty listening and comprehending what people are saying. He hears the words but some of them now seem unfamiliar. This improves when he is spoken to very slowly and deliberately; however, he then has difficulty responding to his clients. As he put it, *"I know what I want to say, I just can't get it out"*. As a result, he doesn't believe it is fair to his clients, or ethical, to continue to try to provide therapy when he is unable to listen and give them the proper guidance, direction, and feedback. He is attempting to complete his book as quickly as he can due to the unpredictable amount of time he has to complete it. His application for social security disability is in preparation. His wife and he are attempting to spend as much quality time together as possible as they know that his life will be cut short by this illness. Needless to say, their teenage son is losing his father to this devastating disease at a sensitive time in his life not to mention the uncertainty of financing for his future education.

While the healthcare community and society at large have an understanding of Alzheimer's disease, its symptoms, treatment, and management, PPA remains unknown to many practitioners and is seen as rare or "atypical". Affected individuals and their families are often frustrated by physicians who diagnose behavior and personality changes of young onset as psychiatric in origin (eg. a life crisis or an "adjustment reaction"). Sometimes individuals and families have visited many healthcare providers before they find one who understands what is happening and is able to lead the person and family in the right direction. It is not uncommon in specialty clinics that evaluate these more unusual forms of dementia for a patient to have had one or more prior evaluations with misdiagnosis.

As a result, it is unknown how many people suffer from Primary Progressive Aphasia. As you have heard from my colleagues, an accurate diagnosis of dementia is medically challenging and primary care physicians have little experience with young onset dementia particularly. I often hear that patients and families have gone two years or more without a diagnosis. They tell me that it is difficult watching a family member changing and not knowing what to do for them.

As we all know in this room, the ability to work, to hold a job and make a contribution is an extremely important value in our society. Not only does it give us the means to meet our basic needs such as food, clothing and shelter, for those of us who are fortunate enough, our work is what also helps keep our lives rich and meaningful. For people with young onset Alzheimer's and Primary Progressive Aphasia, there is a struggle in finding meaningful activity after work has ended. There are very few services focused on those with early onset dementia. One of our families stated to me recently – *“Trying to find adult day care facilities or respite care for physically active patients is next to impossible or too costly to use. We found that adult day care staff do not have training to deal with younger dementia patients. They are better prepared to deal with the needs of older individuals.”* Another stated *“Many nursing homes would not consider him because he is too young and would not fit in. One nursing home indicated he would be a risk to employees just because he was a young male patient.”* As a result, persons with young onset dementia are forced to choose among services set up with other age groups in mind or try to find professional caregivers to provide one-on-one supervision and companionship.

Lastly, I will end with a remark on health insurance. The two-year waiting period for Medicare is extremely difficult. While people try to use COBRA or another form of insurance until they become eligible for Medicare, there is often a gap where they are left uninsured.

Public awareness of younger onset dementias, the variability in presenting symptoms and the importance of careful differential diagnosis is essential to providing the most accurate and helpful services, education and support. This public hearing is a valuable step in this direction. In order to achieve these goals it is vital to extend the compassionate allowance list to include young onset Alzheimer's disease and related dementias such as primary progressive aphasia; however, this should also include adequate safeguards that prevent misdiagnoses. This will allow patients like James and his family and others like him to obtain the financial support they need at a critical juncture in their lives.

Thank you for holding this meeting and for your consideration of my statement.